Citizen Brief

Engaging with Patients, Families and Caregivers to Support Ontario Health Teams

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McMaster University | HEALTH FORUM

RISE
Rapid-Improvement Support and Exchange

EVIDENCE >> INSIGHT >> ACTION

Rapid-Improvement Support and Exchange (RISE)

RISE's mission is to contribute to the Ontario Ministry of Health's 'one window' of implementation supports for Ontario Health Teams by providing timely and responsive access to Ontario-based 'rapid-learning and improvement' assets.

About citizen panels

A citizen panel is an innovative way to seek public input on high-priority issues. Each panel brings together 14-16 citizens from all walks of life. Panel members share their ideas and experiences on an issue, and learn from research evidence and from the views of others. A citizen panel can be used to elicit the values that citizens feel should inform future decisions about an issue, as well as to reveal new understandings about an issue and spark insights about how it should be addressed.

About this brief

This brief was produced by RISE to serve as the basis for discussions by the citizen panel about engaging patients, families and caregivers to support Ontario Health Teams. This brief includes information on this topic, including what is known about:

- the underlying problem;
- three possible elements of an approach to addressing the problem; and
- potential barriers and facilitators to implement these elements.

This brief does not contain recommendations, which would have required the authors to make judgments based on their personal values and preferences.

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Key Messages

What's the goal?

- The goal of the citizen panel is to take the first step in producing guidance for Ontario Health Teams (OHTs) about engaging patients, families and caregivers.

What's the problem?

- Meaningfully engaging patients, families and caregivers in the work of all OHTs, requires overcoming four issues:
  - OHTs are working in a fast-paced, complex and uncertain environment;
  - there is variability across OHTs in their capacity to engage patients, families and caregivers;
  - current guidance about patient, family and caregiver engagement has not yet been tailored to the specific context of OHTs; and
  - people from diverse social, economic and cultural backgrounds may face additional barriers to their involvement in co-design.

What do we know about elements of a potentially comprehensive approach for addressing the problem?

- **Element 1:** Supporting patient, family and caregiver engagement at all levels and stages of OHT implementation
  - This element focuses on key principles (including the Patient Declaration of Values for Ontario) and promising ways to support engagement at all levels of OHTs (including the service or program level, the organizational level, and the local-system level), as well as different stages and implementation of OHTs.
- **Element 2:** Engaging patients, families and caregivers related to the year-1 priority populations identified by OHTs
  - This element focuses on engaging patients, families and caregivers in a population-health management approach to improve the health outcomes of the priority population.
- **Element 3:** Engaging patients, families and caregivers in co-designing the OHT building blocks
  - This element aims to identify which OHT building blocks should be prioritized for co-design with patients, families and caregivers.

What implementation considerations need to be kept in mind?

- The biggest barriers to implementing these changes may be the variability in resources available to teams to ensure consistent adoption of guidance.
- The two most promising opportunities are that the health system in Ontario is increasingly putting patient, family and caregiver engagement at its centre, and leveraging a strong, dynamic community of patient partners across the province.

Questions for the citizen panel

>> We want to hear your views about the problem, three elements of a potentially comprehensive approach to addressing it, and how to address barriers to moving forward

Box 1: Questions for the panel

Questions related to the problem

- What do you think are the biggest challenges **OHTs** face in engaging with patients, families and caregivers?
- What do you think are the biggest challenges **patients, families and caregivers** face in engaging with OHTs?

Questions related to the elements of a potentially comprehensive approach to address the problem

- Element 1 – Supporting patient, family and caregiver engagement at all levels and stages of OHT implementation
  - How should the Patient Declaration of Values for Ontario help to guide patient, family and caregiver engagement in OHTs?
    - Are there other principles that should guide patient, family and caregiver engagement in OHTs?
  - What can you do (alongside other OHT partners) to support the adoption of these principles?
  - What are the most promising ways to support engagement at different levels?
  - What are the most promising ways to support engagement at different stages of implementation?

Box 1: Questions for the panel *(continued)*

Questions related to the elements of a potentially comprehensive approach to address the problem

- Element 2 – Engaging patients, families and caregivers related to the year-1 priority populations identified by OHTs
  - What are the most promising ways to engage the year-1 priority populations?
  - What could support or enable **OHTs** to engage these populations?
  - What could support or enable the **year-1 priority populations** to be engaged?

- Element 3 – Engaging patients, families and caregivers in co-designing the OHT building blocks
  - Which building blocks are the most important for patients, families and caregivers (and should be prioritized for co-design)?
  - What role would you like to play (alongside other stakeholders) during the co-design and implementation of these building blocks?

Questions related to implementation considerations

- What are the biggest barriers to pursuing these elements?
- What are the biggest opportunities that could help to implement these elements?

Box 2: Glossary

Care pathways

Proactively offering all components of evidence-based care in an expected care trajectory to those with a particular need for care (for example, hip surgery, diabetes management, and palliative-care services), including how they are sequenced and timed.(2)

In-reach services

Proactively offering evidence-based services that can promote health, prevent disease and help people live well with their conditions anytime they are 'seen in' or 'touched by' the health system.(2)

Out-reach services

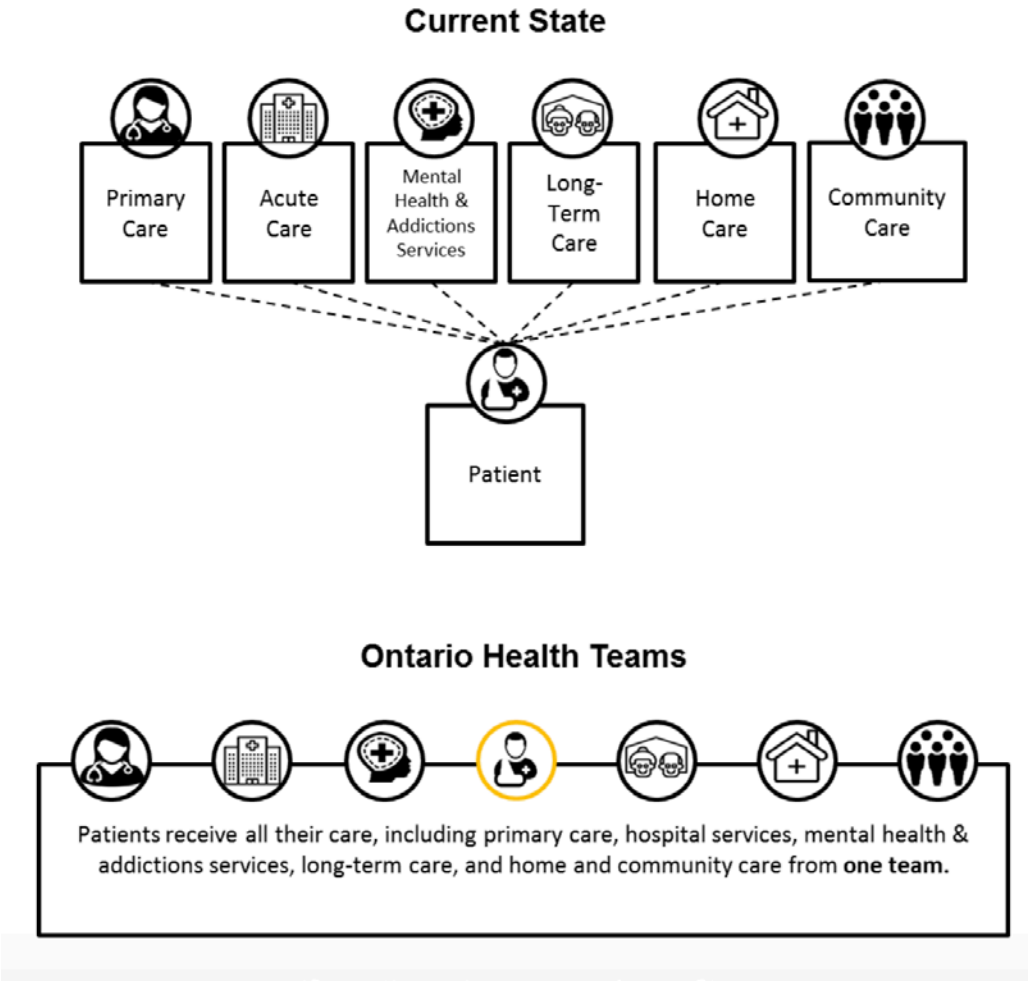
Proactively connecting with those who are not seeking care now (or have not been 'seen' or 'touched' for some time) and again proactively offering evidence-based services in a coordinated way, and removing barriers to accessing these services.(2)

Patients, families and caregivers must play a crucial role in co-designing the new Ontario Health Teams.

The context: Why is engaging patients, families and caregivers to support Ontario Health Teams a high priority?

Ontario is in the midst of major health reforms, among other significant changes is the creation of Ontario Health Teams (OHTs) in which all healthcare providers will work as one coordinated team (see Figure 1). The reforms aim to break down silos in the system, provide more integrated care, and improve population health across Ontario.(3-5)

Figure 1. Creation of the Ontario Health Teams



Source : http://health.gov.on.ca/en/pro/programs/connectedcare/oht/default.aspx

The introduction of OHTs has the potential to become a key development in Ontario's health system. Healthcare-delivery partners across the province have been asked to organize themselves into teams and to begin providing care for a given geographic area and priority year-1 population. After going through a process of submitting a full application to become an OHT as well as a site visit, 24 teams from across the province have been approved as OHTs and are in the process of refining and implementing their vision for how care should be redesigned.(6)

Patient, family and caregiver engagement must play a crucial role in this process. Indeed, such engagement has been identified as one of the eight OHT building blocks (which were called 'OHT requirements' in the ministry's original guidance document). This illustrates

the expectations that OHTs will enable meaningful patient, family and caregiver engagement at all levels of OHTs, from co-designing programs and services to governance structures.(7)

Given the early stage of the current reforms, there is a unique opportunity to ensure that patients, families and caregivers are engaged with all OHTs and helping them to refine their path forward. Your involvement in the panel will help to provide critical guidance about how to meaningfully engage patients, families and caregivers in the work of OHTs, and ultimately how to co-design health and social systems that are aligned with their needs, preferences and aspirations. This citizen brief was prepared to support this conversation. In the following sections, the brief explores some of the challenges to engaging patients, families and caregivers to support OHTs, three possible elements of an approach to addressing these challenges, and potential barriers and facilitators to implement these elements.

People from diverse social, economic and cultural backgrounds may face additional barriers to engagement

The problem: What are the challenges to engaging patients, families and caregivers in the context of OHTs?

Meaningfully engaging patients, families and caregivers in the work of all Ontario Health Teams (OHTs), requires overcoming four issues:

- OHTs are working in a fast-paced, complex and uncertain environment;
- there is variability across OHTs in their capacity to engage patients, families and caregivers;
- current guidance about patient, family and caregiver engagement have not yet been tailored to the specific context of OHTs; and
- people from diverse social, economic and cultural backgrounds may face additional barriers to their involvement in co-design.

Each of these are further discussed in the section below.

OHTs are working in a fast-paced, complex and uncertain environment

OHTs were first announced as a provincial reform in February 2019. Within a year, healthcare organizations and providers across the province have been asked to:

- consider what this change means for the delivery of health services;
- find and develop partnerships with organizations, providers, communities, patients, families and caregivers both within and external to the health system;
- develop trust and an aligned vision among these new partners (which for some teams is over 60 partners);
- define the population and priority population for which each OHT will be accountable;
- make strategic decisions related to each of the eight OHT building blocks;
- complete an application and site visit with the Ministry of Health; and
- design and adopt a population-health management approach (including, care pathways, in-reach services and out-research services) for their year-1 priority population.

Teams have thus far undertaken a tremendous amount of work in trying to transform the health system, most of which has been done without dedicated resources (either monetary or personnel). They are operating within a 'low-rules' environment which, for those without previous experience leading a transformation, may be difficult to navigate. At an in-person gathering of Ontario Health Teams in February 2020 (the Provincial Learning and Improvement Forum), many teams described 'feeling confused, overwhelmed, nervous and encouraged' for upcoming changes.(8)

The meaningful engagement of patients, families and caregivers in this work is critical to its success. Their intimate knowledge of the system, its barriers and their support to develop solutions that can improve care for all makes the case for their early engagement in these reforms. However, given the many other competing demands on OHTs, patient, family and caregiver engagement has sometimes fallen to the back burner.

A further challenge that teams are facing with respect to their capacity to engage is determining how engagement changes alongside the development of OHTs. Many organizations have been used to the process of patient, family and caregiver engagement within a static organization. Partners of the OHT may not know the right methods or extent of engagement that is appropriate at each of the different milestones between

proposal development and full implementation. For example, engagement in the development of the vision for a team and the role that patients, families and caregivers play will look different then in the co-design of programs and services, or in the implementation of new programs and services.

There is variability across OHTs in their capacity to engage patients, families and caregivers

In submitting their full applications to the ministry, OHTs were asked to align their vision with the Patient Declaration of Values for Ontario.(1) A key tenant in the declaration, which was represented through focused questions, is the expectation of having opportunities to be included in policy development and program design at local, regional and provincial levels of the health system. This was operationalized in the applications by asking teams to describe:

- any partnership, engagement or consultation activities that have taken shape;
- how patients', families' and caregivers' feedback was incorporated into the vision for the team; and
- detailed plans about ongoing engagement.(9)

Informal consultations with Ontario Health Teams have revealed variability in the level of engagement. While some Ontario Health Teams have a high engagement with patients, families or caregivers including acting as co-leads of their team, members of governance committees and being a signatory on applications that went to the Ministry of Health. Other teams describe less fulsome engagement, for example, through one-off consultations. These findings may be explained by the interplay of several factors, including variation across OHTs' readiness to engage (meaning their willingness and ability to implement patient, family and caregiver engagement).(10)

To get this reform right, all OHTs will need to be consistently engaging with patients, families and caregivers at a high level and learning from their experiences within the system.

Current guidance about patient, family and caregiver engagement has not yet been tailored to the specific context of OHTs

The ministry laid out its short-term and long-term expectations related to patient, family and caregiver engagement in its guidance document to OHTs (see Table 1 below).(11)

Table 1. Ministry's expectations for OHTs regarding patient, family and caregiver engagement (11)

Readiness criteria for OHT candidates	Year 1 expectations for OHT candidates	Expectations for OHTs at maturity
• Demonstrated history of meaningful patient, family, and caregiver engagement, and support from First Nations communities where applicable • Plan in place to include patients, families and caregivers in governance structure(s) • Put in place patient leadership • Commitment to develop an integrated patient-engagement framework, and patient-relations process • Adherence to the French Language Services Act (as applicable)	• Patient Declaration of Values for Ontario in place • Patients, families and caregivers included in governance structure(s) • Patient leadership established • Patient-engagement framework, patient-relations process, and community-engagement plan are in place	• OHTs will uphold the principles of patient partnership, community engagement, and system co-design • OHTs will meaningfully engage and partner with - and be driven by the needs of - patients, families, caregivers and the communities they serve

While the ministry established their expectations, it did not offer explicit and prescriptive guidance on how to meet those expectations. While a 'low-rules' approach may facilitate and trigger innovation, and the development of locally-based solutions, it can also create uncertainties among OHTs about how to move forward.

It should be noted, that there is a lot of guidance about patient, family and caregiver engagement that has been developed in Ontario and abroad in recent years. However, current guidance has not been tailored to the specific context (and mandate) of OHTs. Table 2 below provides a non-exhaustive list of guidance documents that have been developed in recent years.

Table 2. Non-exhaustive list of guidance documents about patient, family and caregiver engagement

Producers	Documents
OHTs	• Framework for community engagement (East and Downtown East Toronto Ontario Health Teams)
Ontario Health, Quality Business Unit (formerly Health Quality Ontario)	• Choosing methods for patient and caregiver engagement: A guide for health care organizations • Creating and sustaining Patient and Family Advisory Councils: Choosing meaningful projects • Chairing meetings with patient and caregiver advisors: A best practice checklist for health care professional • Engaging with patients and caregivers about quality improvement: A guide for health care providers • Engaging with patients and caregivers about patient relations: A guide for hospitals • Creating and sustaining Patient and Family Advisory Councils – Creating an effective terms of reference • Supporting patients and caregivers to share their stories: A best practice checklist for health care professionals
Other organizations	• Should money come into it? A tool for deciding whether to pay patient-engagement participants (Change Foundation) • LHIN community engagement guidelines (LINHs) • Citizen engagement strategic framework (Seniors Care Network) • Patients as partners: Guide to co-design (King's Fund)

Given their pressing and competing priorities, OHTs may not know that this guidance exists or have the bandwidth to adapt it to this new context. This also highlights the need to strengthen communication across OHTs to share their engagement experiences, and provide support to develop guidance tailored to the context of OHTs.

People from diverse social, economic and cultural backgrounds may face additional barriers to their involvement in co-design

One of the most common challenges cited when engaging patients, families and caregivers in health-system transformations (as well as in health research) is the capacity to engage marginalized populations.(12) This challenge may be fuelled by systemic barriers to engagement (as a result of institutional values, cultures, policies and engagement practices), and by a lack of capacity and skills to engage with these populations proactively and meaningfully.

It is thus common for organizations to pull from the same group of patients, families and caregivers which creates challenges from an equity perspective, and places burden on the same group of individuals. Patients, families and caregivers are a heterogeneous group, whose economic, political, cultural and experiences intersect in multiple ways and influence how they engage (or not) with health systems. This means that people face different health risks and opportunities depending on their social and economic conditions, shaping their risk of disease, the actions they are able to take to prevent and treat conditions, and their interactions through the health system.(13-14) For example, Ontarians living with low socio-economic conditions carry a disproportionate burden of chronic diseases, with higher rates of hospitalizations and deaths.(15)

People who are currently under-served by Ontario's health system may have the most to benefit from OHTs that offer accessible, high-quality health and social services. Interactions between social categories, including race, ethnicity, Indigeneity, gender, class, language, sexuality, geography and ability, among others, and the extent to which existing health and social services account for these in their structures and services, will shape the experience and outcomes of patients, families and caregivers.(16) Those carrying the greatest burden of health inequities need to have a stronger voice in the planning and implementation of their care and the systems meant to support it. OHTs will need to understand the social needs and influencing factors that both facilitate and act as a barrier to diverse and active engagement.

Discussions with OHTs have revealed that teams would be looking to provide services to various populations where gaps in services exist, including:

- Indigenous groups;
- francophone communities;
- refugees and new Canadians;
- lower socio-economic populations;
- lesbian, gay, bisexual, and transgender (LGBTQ);
- homeless;
- marginalized and vulnerable;
- uninsured;
- unattached to primary care; and
- people in supportive care/long-term care.

This means that OHTs will need to 'up their game' in terms of meaningful engagement of patients, families and caregivers with diverse backgrounds.

Strengthening patient, family and caregiver engagement will require the consideration of a number of elements

Elements of an approach to address the problem

>> To promote discussion about the pros and cons of potential solutions, we have selected three elements of an approach to engaging patients, families and caregivers to support OHTs

Many approaches could be selected as a starting point for discussion. We have selected the following three elements of an approach for which we are seeking input:

1. supporting patient, family and caregiver engagement at all levels and stages of OHT implementation;
2. engaging patients, families and caregivers related to the year-1 priority populations identified by OHTs; and
3. engaging patients, families and caregivers in co-designing the OHT building blocks.

These elements should not be considered separately. Instead, each should be considered as contributing to a potentially comprehensive approach to addressing the problem. New elements could also emerge during the discussions.

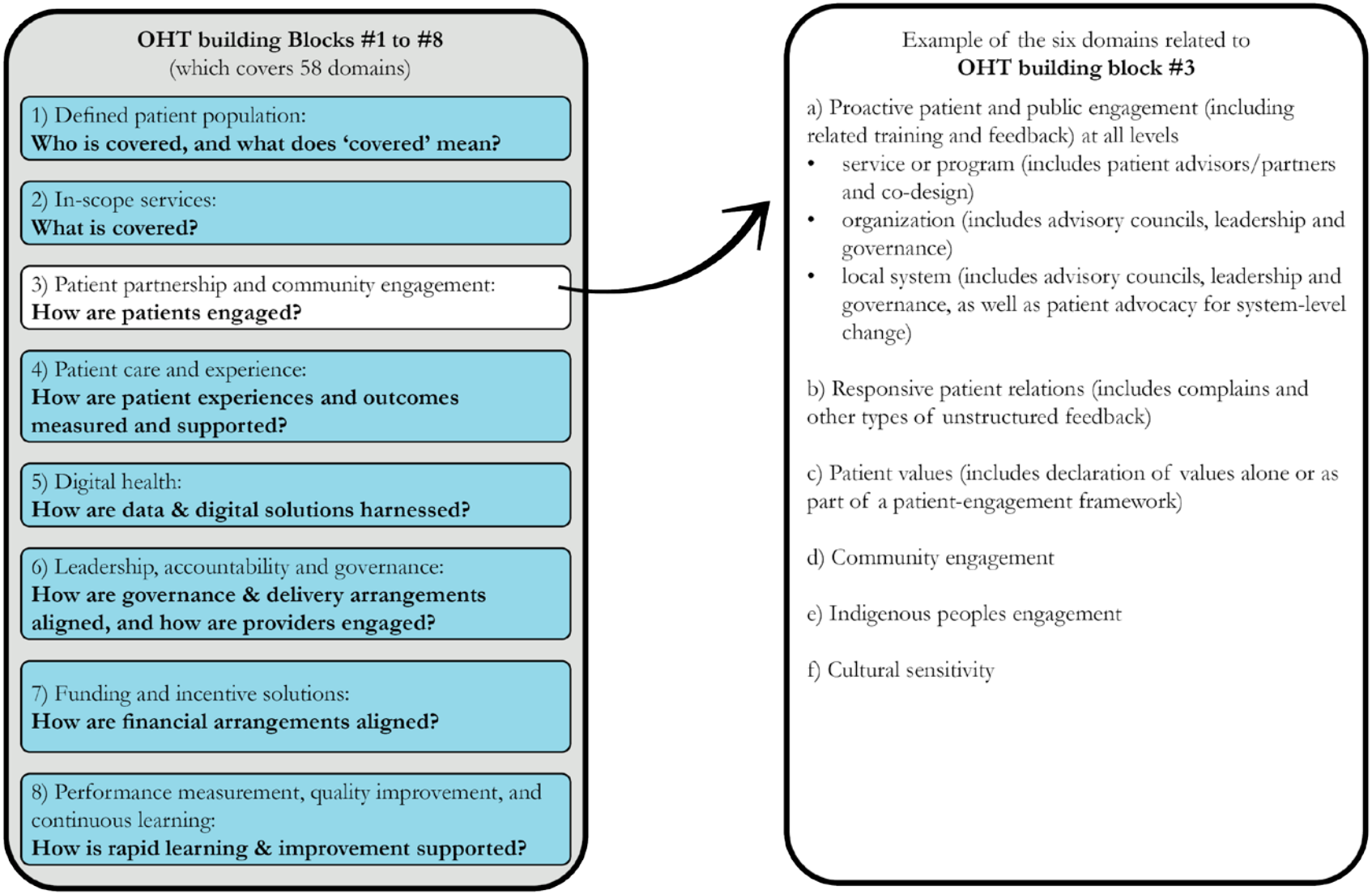
Element 1 – Supporting patient, family and caregiver engagement at all levels and stages of OHT implementation

Overview

This element is focused on OHT building block #3 which relates to patient, family and caregiver engagement (see Figure 2 below). This may include, but is not limited to:

- strategies to engage patients, families and caregivers at all levels of OHTs;
- strategies to engage patients, families and caregivers at different stages of implementation of OHTs; and
- strategies to support OHTs in the adoption of the Patient Declaration of Values for Ontario as a vision of what they are moving towards (see Box 3 below).

Figure 3. OHT building blocks



Box 3: Patient Declaration of Values for Ontario (1)

Respect and Dignity

1) We expect that our individual identity, beliefs, history, culture, and ability will be respected in our care.
2) We expect health care providers will introduce themselves and identify their role in our care.
3) We expect that we will be recognized as part of the care team, to be fully informed about our condition, and have the right to make choices in our care.
4) We expect that families and caregivers be treated with respect and seen as valuable contributors to the care team.
5) We expect that our personal health information belongs to us, and that it remain private, respected and protected.

Empathy and Compassion

1) We expect health care providers will act with empathy, kindness, and compassion.
2) We expect individualized care plans that acknowledge our unique physical, mental and emotional needs.
3) We expect that we will be treated in a manner free from stigma and assumptions.
4) We expect health care system providers and leaders will understand that their words, actions, and decisions strongly impact the lives of patients, families and caregivers.

Accountability

1) We expect open and seamless communication about our care.
2) We expect that everyone on our care team will be accountable and supported to carry out their roles and responsibilities effectively.
3) We expect a health care culture that values the experiences of patients, families and caregivers and incorporates this knowledge into policy, planning and decision making.
4) We expect that patient/family experiences and outcomes will drive the accountability of the health care system and those who deliver services, programs, and care within it.
5) We expect that health care providers will act with integrity by acknowledging their abilities, biases and limitations.
6) We expect health care providers to comply with their professional responsibilities and to deliver safe care.

Box 3: Patient Declaration of Values for Ontario (continued)

Transparency

1) We expect we will be proactively and meaningfully involved in conversations about our care, considering options for our care, and decisions about our care.
2) We expect our health records will be accurate, complete, available and accessible across the provincial health system at our request.
3) We expect a transparent, clear and fair process to express a complaint, concern, or compliment about our care and that it not impact the quality of the care we receive.

Equity and Engagement

1) We expect equal and fair access to the health care system and services for all regardless of language, place of origin, background, age, gender identity, sexual orientation, ability, marital or family status, education, ethnicity, race, religion, socioeconomic status or location within Ontario.
2) We expect that we will have opportunities to be included in health care policy development and program design at local, regional and provincial levels of the health care system.

Questions to consider

- How should the Patient Declaration of Values for Ontario help to guide patient, family and caregiver engagement in OHTs?
  - Are there other principles that should guide patient, family and caregiver engagement in OHTs?
- What can you do (alongside other OHT partners) to support the adoption of these principles?
- What are the most promising ways to support engagement at **different levels**? (Use Worksheet 1 below)
- What are the most promising ways to support engagement at **different stages** of implementation? (Use Worksheet 2 below)

Worksheet 1. Promising ways to support engagement at different levels

LEVELS	SPECTRUM OF ENGAGEMENT APPROACHES (17)			
	SHARE *Provide easy-to - understand health information*	**CONSULT** *Get feedback on a health issue (for example, a policy or decision)*	**DELIBERATE** *Discuss an issue and explore solutions*	**COLLABORATE** *Partner to address an issue and apply solutions*
Service or program	•	•	•	•
Organization	•	•	•	•
Local system	•	•	•	•

Worksheet 2. Promising ways to support engagement at different stages of implementation of OHTs

STAGES OF IMPLEMENTATION FOR OHTs	SPECTRUM OF ENGAGEMENT APPROACHES (17)			
	SHARE *Provide easy-to - understand health information*	**CONSULT** *Get feedback on a health issue (for example, a policy or decision)*	**DELIBERATE** *Discuss an issue and explore solutions*	**COLLABORATE** *Partner to address an issue and apply solutions*
Self-assessing readiness *Interested groups of providers and organizations assess their readiness and begin working to meet key readiness criteria for implementation*	•	•	•	•
Validating provider readiness *Based on Self-Assessments, groups of providers are identified as being In Discovery or In Development stages of readiness*	•	•	•	•
Becoming an OHT candidate *Groups of providers that demonstrate, through an invitational, full application, that they meet key readiness criteria are selected to begin implementation of the OHT model*	•	•	•	•
Becoming a designated OHT *OHT candidates that are ready to receive an integrated funding envelope and enter into an OHT accountability agreement with the funder can be designated as an OHT*	•	•	•	•

Element 2 – Engaging patients, families and caregivers related to the year-1 priority populations identified by OHTs

Overview

To be successful in this transformation, Ontario Health Teams will need to adopt a population-health management approach.(2) Population-health management involves broadening the focus of services from being reactive to the needs of those who "walk in the door" to being proactive in meeting the needs of the entire population for which they are accountable.(2) Successfully implementing population-health management means improving the health of the entire population.(18)

There are four steps involved in population-health management:

1) segment the population into groups with shared needs (for example, demography, prior conditions, prior service use), which allows you to better understand who is in your population and how their needs vary;
2) co-design care pathways, in-reach services and out-reach services to meet the needs of each of the groups you have identified;
3) implement these pathways and services that support patients to get the care they need; and
4) monitor implementation and evaluate the impact of these changes.(2)

Critical to this work is the engagement of patients, families and caregivers. While those involved in planning the OHTs are able to understand some quantitative indicators of risks facing patients, families and caregivers, this only tells part of the story. It is vital to understand the barriers that individuals face to getting the care they need (such as poverty, unstable housing, language or cultural barriers, poor health literacy, or family violence) and the types of solutions that they would design to improve care pathways and access to services.

Adopting a population-health management approach will require OHTs to engage with individuals and their communities, work with governments and population-health agencies to intersect emerging issues, and develop multidisciplinary and inter-sectoral collaborations to provide higher care standards.(19-20) It will also be pivotal to engage those who are most in need to develop care pathways and services that are aligned to their needs, preferences and values.

While OHTs will be looking to provide services to various populations where gaps in services exist, several OHTs have focused on the following groups as their year-1 priority population:

- people at the end of life and/or needing palliative care;
- older adults with greater needs (meaning those at risk, with multiple chronic conditions, complexity and frailty);
- people with chronic conditions (including those with congestive heart failure; chronic obstructive pulmonary disease, dementia, diabetes, and complex-care needs); and
- people with mental health and addictions issues.(21)

Questions to consider

- What are the most promising ways to engage the year-1 priority populations? (Use Worksheet 3 below)
- What could support or enable **OHTs** to engage these populations?
- What could support or enable the **year-1 priority populations** to be engaged?

Worksheet 3. Promising ways to engage the year-1 priority populations identified by OHTs

EXAMPLES OF POPULATIONS MOST IN NEED	SPECTRUM OF ENGAGEMENT APPROACHES (17)			
	SHARE *Provide easy-to - understand health information*	**CONSULT** *Get feedback on a health issue (for example, a policy or decision)*	**DELIBERATE** *Discuss an issue and explore solutions*	**COLLABORATE** *Partner to address an issue and apply solutions*
People at the end of life and/or needing palliative care	•	•	•	•
Older adults with greater needs (meaning those at risk, with multiple chronic conditions, complexity and frailty)	•	•	•	•
People with chronic conditions (including those with congestive heart failure, chronic obstructive pulmonary disease, dementia, diabetes, and complex-care needs)	•	•	•	•
People with mental health and addictions issues	•	•	•	•

Element 3 – Engaging patients, families and caregivers in co-designing the OHT building blocks

Overview

OHTs will initially need to learn and improve rapidly in the design of each of the eight OHT building blocks, which were called 'OHT requirements' in the ministry's original guidance document (See Table 3 below). Designing these building blocks will require strategic choices in 58 domains, with some of these decisions needing to be made in year 1 and others coming later.

Table 3. OHT building blocks

OHT building block	Description
#1 Defined patient population (who is covered, and what does 'covered' mean?)	Identify a target population for year 1 and a geographic population based on local factors and how patients typically access care at maturity. Examples of domains included: target-population definitions, geographic area definitions, and patient access targets (among others)
#2 In-scope services (what is covered?)	Provide a full and coordinated continuum of care to achieve better patient and population health outcomes at maturity. Examples of domains included: service-inclusion definitions; service-exclusion definitions; and service site decisions
#3 Patient partnership and community engagement (how are patients engaged?)	Uphold the principles of patient partnership, community engagement and system co-design and commit to develop an integrated patient engagement framework that adheres to the French Language Services Act, as applicable. Examples of domains included: proactive patient and public engagement, responsive patient relations, and patient values.
#4 Patient care and experience (how are patient experiences and outcomes measured and supported?)	Offer patients, families and caregivers the highest quality care and best experience possible including making 24/7 coordination and system navigation services to those who need it to ensure transitions will be seamless. Examples of domains included: proactive patient identification, individualized care planning, and digital access to health information.

#5 **Digital health** (how are data and digital solutions harnessed?)	Record and share digital information with OHT partners and adopt digital options for decision support, operational insights, population health management, and tracking/reporting key indicators. Examples of domains included: patient portal, electronic medical record, and digital health tools including their selection and implementation.
#6 **Leadership, accountability and governance** (how are governance and delivery arrangements aligned, and how are providers engaged?)	Determine a governance structure through which teams are able to operate through a single clinical and fiscal accountability framework and will include appropriate financial management and controls. Examples of domains included: distributed cross-sectoral leadership capabilities, collaborative governance, and culture of teamwork, collaboration and adaptability.
#7 **Funding and incentive structure** (how are financial arrangements aligned?)	Demonstrate a track record of responsible financial management, understanding of population costs and cost drivers, and preparation for prospective funding through an integrated funding envelope based on the care needs of the attributed population. Example of the domains included: population cost and cost drivers, integrated fund holding, and contracts including gain- and risk-sharing.
#8 **Performance measurement, quality improvement, and continuous learning** (how OHTs are supported to learn and improve rapidly?)	Provide care according to best available evidence and clinical standards, with an ongoing focus on quality improvement and achieving indicators aligned with the quadruple aim. Example of the domains included: performance measurement, guidelines and other sources of best evidence, and local area focused rapid learning and improvement.

Questions to consider

- Which building blocks are the most important for patients, families and caregivers (and should be prioritized for co-design)?
- What role would you like to play (alongside other stakeholders) during the co-design and implementation of these building blocks?

Implementation considerations

It is important to consider what barriers we may face if we implement the proposed elements of a potentially comprehensive approach to address the problem. These barriers may affect different groups (for example, patients, caregivers, healthcare providers), different healthcare organizations or the health system. While some barriers could be overcome, others could be so substantial that they force a re-evaluation of whether we should pursue that element. Use Worksheet 4 below to think about potential barriers to implementing the elements.

Worksheet 4: Potential barriers to implementing the elements

Element	Description of potential barriers	Other barriers
Element 1 – Supporting patient, family and caregiver engagement at all levels and stages of OHT implementation	• Some OHT partners may face difficulties in developing a shared vision, quality guidelines and metrics about patient, family and caregiver engagement given their constraints and competing priorities • Some OHT partners may be reluctant to move forward if they lack the capacity to monitor progress in achieving patient, family and caregiver engagement (including logic models, evaluation tools and metrics) • Some OHT partners may be unwilling to participate in developing or implementing new engagement practices that could challenge their authority and resources • Some OHT partners may grapple with prevalent and persistent misconceptions about what 'patient and caregiver engagement', 'community engagement', 'patient leadership' and 'co-design' mean • Some OHT partners may lack champions or agents of change necessary to adopt and sustain patient- and caregiver-engagement innovations	• *Other examples (fill here):*

	• Some OHT partners may be unwilling or uninterested in making long-term sustainable financial commitments towards building engagement capacities due to current uncertainties facing OHTs	
Element 2 – Engaging patients, families and caregivers related to the year-1 priority populations identified by OHTs	• Some OHTs may lack the knowledge/skills/infrastructures to engage with hard-to-reach populations • Some stakeholders may challenge engagement efforts on the grounds that they are not representative of Ontario's diverse population (for example, in terms of place of residence, race, ethnicity, culture, occupation, gender, religion, educational level, socio-economic status, and level of social capital/social exclusion) • Patients and caregivers may be frustrated by past engagement efforts by OHT partners which they may feel have not meaningfully influenced how the health and social systems are evolving • Many patients, families and caregivers (particularly those most in need) may not know about the major reforms underway, thus they may not see the value in being engaged with OHTs • Those most in need may face persistent systemic barriers to engagement	• *Other examples (fill here):*
Element 3 – Engaging patients, families and caregivers in co-designing	• Patients and caregivers may be frustrated by past engagement efforts by OHT partners which they may feel have not meaningfully influenced how the health and social systems are evolving • Many patients, families and caregivers may not know about the major reforms	• *Other examples (fill here):*

the OHT building blocks	underway, thus they may not see the value in being engaged with OHTs • Some patient, family and caregiver partners may be overwhelmed by all the pressing and competing demands they receive (and may lack adequate support) • Some patient and caregiver organizations may be reluctant to partner with OHTs because it may be perceived as a threat to their independence	

The implementation of each of the three elements could also be influenced by the ability to take advantage of potential windows of opportunity. A window of opportunity could be, for example, a recent event that was highly publicized in the media, a crisis, a change in public opinion, or an upcoming election. A window of opportunity can facilitate the implementation of an element. Use Worksheet 5 below to think about possible windows of opportunity.

Worksheet 5: Potential opportunities for implementing the elements

Element	Description of potential opportunities	Other opportunities
Element 1 – Supporting patient, family and caregiver engagement at all levels and stages of OHT implementation	• The health system in Ontario is increasingly putting patient and caregiver engagement at its centre (22) • OHT partners can draw from the rich experience of patient and caregiver engagement in Ontario, such as: o Patient and Family Advisory Councils (PFACs) or their equivalent (for example, Ontario Citizens' Council; Patient and Caregiver Advisory Table for Home and Community Care) help to set direction at the Ministry of Health, in Local Health Integration Networks (LHINs), and for community-governed primary-care teams o Ontario Health, Quality Business Unit (formerly Health Quality Ontario - HQO) led several initiatives on patient partnering in quality improvement (for example, patient-engagement tools and resources, and patient advisors program) o Ontario Health, Quality Business Unit, the Association of Family Health Teams of Ontario and the Alliance for Healthier Communities developed resources to support primary-care organizations in patient engagement • There are opportunities to learn from organizations in other jurisdictions that have extensive	• *Other examples (fill here):*

	patient- and caregiver-engagement experiences (some of which are currently evaluating their practices and can serve as models for consideration within the Ontario context) • Ontario SPOR SUPPORT Unit (OSSU) has supported three masterclasses on the conduct and use of patient-oriented research (for patients as well as providers, policymakers and researchers), as well as smaller engagement projects and patient-partnership training workshops • Many research groups and 'intermediary groups' (for example, the Change Foundation) work with a standing citizen panel, and the McMaster Health Forum convenes citizen panels on a range of health and social-system topics • Patient and Public Engagement Evaluation Tool (PPEET), and a broader Public Engagement Evaluation Toolkit, can be used to evaluate patient, family and caregiver engagement • The Canadian Foundation for Healthcare Improvement hosts a resource hub to support patient engagement in healthcare, and has established a collaborative initiative (Partnering with Patients and Families for Quality Improvement), which provided funding, coaching and other support for healthcare organizations that engage patients and families in designing, delivering and evaluating health and social care	

Element 2 – Engaging patients, families and caregivers related to the year-1 priority populations identified by OHTs	• The adoption of a population-health management approach (and its emphasis on segmenting populations and identifying those most at risk) may create an incentive for OHTs to proactively engage those most in need	• *Other examples (fill here):*
Element 3 – Engaging patients, families and caregivers in co-designing the OHT building blocks	• There is an opportunity to leverage a strong and dynamic community of patient partners/advisors across the province that are formally (for example, the Patient Advisors Network) or informally connected o Patients, families and caregivers engaged with OHTs have expressed the desire to network as part of a community of practice	• *Other examples (fill here):*

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Merit review

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